

## **Measurement of functional change in ambulant Duchenne muscular dystrophy (DMD) boys**

*By Scott, Elaine*

Many scales have been developed to assess the functional abilities of patients with neuromuscular disease. These are generally ordinal or comprised of a number of separate categories each with an ordinal grading scale, which are then summed to provide a total 'score'.

Use of such scales in the measurement of change pose problems in evaluation as the distance between intervals is not known, an 'ordinal number' being a definition of an observed attribute, the assigned number having no arithmetic properties. There is a risk of misinference from results, or scores may be uninterpretable.

To address this issue the North Star Project is investigating the use of the TELER® Measurement System in the analysis of functional change in ambulant DMD boys. The scale items (codes) of a valid TELER indicator are described in terms of clinically significant outcomes and clinically significant changes in a patient's abilities. A prerequisite for the development of an indicator is the use of evidence-based knowledge. The entity 'clinically significant change' can be counted, allowing for the performance of meaningful arithmetic and therefore valid interpretation of results.

Five indicators describing aspects of physical ability have been developed. Work is underway to assess their validity, reliability and responsiveness.

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